

# **Bridging the Gaps: An Inside Out View of Autism**

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(Or, Do You Know What I Don't Know?)

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In May of 1989 I drove 1200 miles to attend the tenth annual TEACCH conference, where I learned that autistic people can't drive.

No, let's see if I can make that a little less simplistic: In May of 1989 I drove 1200 miles to attend the tenth annual TEACCH conference, where I spent two days among people who knew something about what autism means. They didn't think being autistic means being mentally retarded, being emotionally disturbed, or being deliberately obnoxious. They didn't think being spaced out means not paying attention. They didn't think an uneven performance means not trying. They did know about spacing out, and about sensory overload, and about not understanding things other people take for granted. They had a vocabulary for talking about my life.

And almost ten years after I struggled through driver's training wondering what was wrong with me that I had so much trouble learning to drive, I learned there was an awful lot right with me that I learned to drive at all.

I've been living with autism for 27 years. But I'm just beginning to learn about what that means. I grew up hearing the word but never knowing what was behind it. My parents did not attend programs to learn about autism, did not collect literature to educate schools about autism, did not explain, to me or to anyone else, why my world was not the same one that normal people live in.

(Should parents tell their autistic children that they are autistic? I think so. If the children notice words at all, they already know the word is being used about them. But be sure to tell them what it means. I was told that it meant, among other things, being dumb, crazy, malicious, uncaring, and unmotivated.)

It wasn't so much new facts that I got from this conference. It was new meanings and new perspectives for understanding the facts. I heard professionals describing problems autistic people have, not problems autistic people are. I heard parents recognizing their children's difficulties, instead of casting themselves as victims of their children's existence. I heard professionals acknowledging their own limitations, without blaming their clients when the help they have to offer is not enough. I heard parents talking about their own frustrations and disappointments, without accusing their children of cheating them by being what they are. Above all, I heard people discussing autism in terms of not understanding, rather than not caring.

I understand a lot about not understanding. I usually understand when I don't understand something, and I'm beginning to be able to recognize gaps between what I actually understand and what other people assume I understand. Some of the missing connections that I can finally name are funny, and some are sad, and some are infuriating. I'm sure there are many that I haven't noticed or that I don't have words for yet. But here are some of the words that I have found, and here are some of the gaps that I hope they can help fill.

## **Being Autistic Does Not Mean Being Mentally Retarded**

Being autistic does not mean being unable to learn. But it does mean there are differences in how learning happens. Input-output equipment may work in non-standard ways. Connections between different sensory modes or different items of stored data may be atypical; processing may be more narrowly or more broadly focused than is considered normal. But what I think is

even more basic, and more frequently overlooked, is that autism involves differences in what is known without learning.

Simple, basic skills such as recognizing people and things presuppose even simpler, more basic skills such as knowing how to attach meaning to visual stimuli. Understanding speech requires knowing how to process sounds—which first requires recognizing sounds as things that can be processed, and recognizing processing as a way to extract order from chaos. Producing speech (or producing any other kind of motor behavior) requires keeping track of all the body parts involved, and coordinating all their movements. Producing any behavior in response to any perception requires monitoring and coordinating all the inputs and outputs at once, and doing it fast enough to keep up with changing inputs that may call for changing outputs. Do you have to remember to plug in your eyes in order to make sense of what you're seeing? Do you have to find your legs before you can walk? Autistic children may be born not knowing how to eat. Are these normally skills that must be acquired through learning? These are the gaps that I notice most often: gaps between what is expected to be learned and what is assumed to be already understood. Even when I can point to the gap and ask for information about what goes there, my questions are usually ignored, treated as jokes, or met with incredulity, suspicion, or hostility. I'm penalized for my intelligence—people become impatient when I don't understand things they think I'm "smart enough" to know already or to figure out for myself.

Being bright only means I'm good at learning; it doesn't mean I know things without having to learn them first. Figuring things out and finding connections between different parts of a whole are what I do best, and I get a lot of practice because not many of the connections go into place by themselves. But I still have to know what all the parts are before I can find the connections between them.

Assumptions that I know things which in fact I don't understand often lead directly to conclusions that I can't learn things which in fact I already know. Such assumptions nearly led to my being placed in an institution. Because I didn't use speech to

communicate until I was twelve, there was considerable doubt about whether I would ever be able to learn to function independently. No one guessed how much I understood, because I couldn't say what I knew. And no one guessed the critical thing I didn't know, the one missing connection that so much else depended on: I didn't communicate by talking, not because I was incapable of learning to use language, but because I simply didn't know that that was what talking was for. Learning how to talk follows from knowing why to talk—and until I learned that words have meanings, there was no reason to go to the trouble of learning to pronounce them as sounds. Speech therapy was just a lot of meaningless drills in repeating meaningless sounds for incomprehensible reasons. I had no idea that this could be a way to exchange meaning with other minds.

Not all the gaps are caused by my failure to share other people's unthinking assumptions. Other people's failure to question their assumptions creates at least as many barriers to understanding. The most damaging assumptions, the causes of the most painful misunderstandings, are the same now as they were when I was a child who couldn't talk, a teenager who couldn't drive, and a college student who couldn't get a job: assumptions that I understand what is expected of me, that I know how to do it, and that I fail to perform as expected out of deliberate spite or unconscious hostility.

Other people's assumptions are usually much more resistant to learning than my ignorance. As a graduate student I encountered these assumptions in employers who had extensive backgrounds in special education. Presumably these people (one of whom was the director of a university affiliated facility) had access to up-to-date information about developmental disabilities. But they never bothered to apply that information to the things they "knew" without thinking, and the things they expected me to know without learning.

At the same time I had a friend—not a parent driven by love and obligation to want to reach me, not a professional who made a career of studying my condition, but just someone who thought I was interesting enough to want to get to know better—I had a

friend who, with no formal background in psychology or special education, figured out for herself some guidelines for relating to me. She told me what they were: never to assume without asking that I thought, felt, or understood anything merely because she would have such thoughts, feelings, or understanding in connection with my circumstances or behavior; and never to assume without asking that I didn't think, feel, or understand anything merely because I was not acting the way she would act in connection with such thoughts, feelings, or understanding. In other words, she learned to ask instead of trying to guess.

Are these really such difficult ideas to grasp? Are there people who are so certain they know without learning what other people are inside that they can't learn to understand anyone who isn't like them? Is that what it means to have "empathy"?

## **Being Autistic Does Not Mean Being Emotionally Disturbed**

Not all the gaps involve facts and ideas. A woman at the conference wondered how she could help her autistic daughter to be able to talk about her feelings. I asked if she had ever tried to teach her daughter what feeling-words mean. Did she talk to her daughter about her own feelings? Did she describe what the feelings felt like, instead of just naming them? There's a difference between being aware of one's feelings and knowing what the feelings are called. There's also a difference between having feelings and having automatic connections between feelings and expressions.

When I was growing up autism was considered an emotional disorder. I spent most of my childhood in one or another type of psychotherapy with therapists who started with the assumption that I knew what the words meant, but didn't know how to monitor my own processing. Their interventions primarily consisted of coaching me to say things I did not feel, and of telling me (and telling my parents) that I was behaving strangely because of various bizarre emotional conflicts that the therapists earnestly wished to work through with me.

If I said that wasn't how I felt, especially if I didn't know words to describe how I did feel, I was told (and my parents were told, of course) that I was resisting therapy and did not want to get well. If I obediently repeated the words and remained autistic anyway, I was told that I still wasn't being open enough with my feelings. Occasionally, under extreme circumstances such as the time I broke a bone, I was able to attach words to a subjective experience and make a simple statement such as "my foot hurts." Even when I could find words, no one believed me. I was told that I was only pretending to feel pain, fear, confusion, or whatever I was reporting because I really felt whatever the therapist's preferred theory predicted I should feel.

And through all this condescending concern about feelings and emotional issues, no one ever bothered to explain to me what the words meant! No one ever told me that they expected to see feelings on my face, or that it confused them when I used words without showing corresponding expressions. No one explained what the signals were or how to use them. They simply assumed that if they could not see my feelings, I could not feel them. I think this shows a serious lack of perspective-taking! I finally started learning to talk about feelings when I was twenty-five. I knew someone then who taught me a vocabulary. She didn't know that was what she was doing. She didn't do it because she wanted to help an autistic person learn to "deal with" feelings. She just happened to be someone who talked a lot about her own feelings. She identified what each feeling was called, and where she felt it, and how it felt, and what her face and body were doing about it. When I asked questions about what the words meant, she explained. When she asked questions about my feelings, and I asked for clearer definitions of what she was asking, she clarified the questions until I could answer them. That's all it took to get started; once I realized that words could be used for subjective experiences too, I took off again the way I did with idea-words when I was twelve.

A professional at the conference remarked that therapy with an autistic person is educational therapy, not psychotherapy. Call it educational therapy, interaction therapy, common-sense explanation therapy—or just call it honest and direct

communication. Whatever you call it, a few months of informal, amateur, even accidental non-psychotherapy did more for my ability to express feelings than decades of professional doubletalk. If professionals are to be more helpful than casual friends, they should be more objective than lay people, more willing to explain, less eager to jump to conclusions, more open to questioning their own beliefs.

Assumptions about emotions cause the most impenetrable barriers to understanding, the most devastating damage to relationships, the most harmful interventions, the most irreversible oversights: assumptions that I don't have, don't understand, or can't control my own desires and motivations; that comprehension or communication problems stem from my own conscious or unconscious choices to sabotage functions that would be intact if I truly wanted to use them; that if I fail it's because I don't care enough to succeed; that if I finally succeed, it's because I knew how to do it all along. I've read a lot about how psychodynamic theories blame and harm parents by attributing autism to emotional disturbance. They don't harm the parents nearly as much as they harm the victim when they say a child chooses to be autistic.

The results of these assumptions are often subtle, but they're pervasive and pernicious: I am not taken seriously. My credibility is suspect. My understanding of myself is not considered to be valid, and my perceptions of events are not considered to be based in reality. My rationality is questioned because, regardless of intellect, I still appear odd. My ability to make reasonable decisions, based on my own carefully reasoned priorities, is doubted because I don't make the same decisions that people with different priorities would make. I'm accused of being deliberately obtuse because people who understand the things I don't understand can't understand how anyone can possibly not understand them. (That sentence makes perfect sense. If you have to work a little bit to process it, you may get a slight taste of what it's like to have a language processing problem.) My greatest difficulties are minimized, and my greatest strengths are invalidated.



I have an interface problem, not a core processing problem. I can't always keep track of what's happening outside myself, but I'm never out of touch with my core. Even at worst, when I can't focus and I can't find my body and I can't connect to space or time, I still have my own self. That's how I survive and how I keep growing.

I taught myself to read at three, and I had to learn it again at ten, and yet again at seventeen, and at twenty-one, and at twenty-six. The words that it took me twelve years to find have been lost again, and regained, and lost, and still have not come all the way back to where I can be reasonably confident they'll be there when I need them. It wasn't enough to figure out just once how to keep track of my eyes and ears and hands and feet all at the same time; I've lost track of them and had to find them over and over again.

But I have found them again. The terror is never complete, and I'm never completely lost in the fog, and I always know that even if it takes forever, I will find the connections and put them back together again. I know this because I'm always connected at the core and I never lose track of my own self. This is all I have that I can always count on, all I have that is truly my own. And this is what is denied when I'm told that I bring problems on myself because I'm not stable at the core.

## **Being Autistic Does Not Mean Being Uncaring**

There are other gaps that I'm just beginning to notice, and other assumptions that I'm just beginning to explore. They have to do with interpersonal rather than intrapersonal processing. The assumptions are similar: that I have the same needs for relationships that other people have, that I know how to relate in ways that are considered normal, and that I don't relate normally because I have negative or uncaring attitudes toward other people.

As with other activities I've mentioned, social interactions

involve things that most people know without having to learn them. At the conference I met some other autistic people and gained a new insight into how non-autistic people think. During the Thursday evening workshop sessions, a room was set aside for autistic people to meet informally in an unstructured setting. Four of us were left alone together. Within a few minutes, one person was rambling without enough focus, one was obsessing on a too-narrow focus, and I was having trouble keeping track of both of them at once. The fourth person in the room was invisible. That was interesting to watch; I know I'm invisible sometimes, but I'd never seen how it looks from outside.

After a while some other people came in to see what autistic people talk about, and they started asking questions that gave some structure to the conversation. Then some interesting things came out. I even heard the invisible person talk. While I could guess how odd he must have looked and sounded to people who are always connected to their bodies, it was exciting to see him putting his verbal mode on-line, to hear how far from his voice he was, and to be able to recognize the kinds of bridges he was building, because they were the same kinds of bridges I build myself. I build them over and over again every day, and no one ever notices unless I slip, but I noticed when I saw someone else building them.

All this happened because some people who weren't autistic came in and asked questions. A computer—or an autistic person—might have predicted what would happen if people who were all impaired in their abilities to communicate and converse were left together with no direction. (This autistic person did predict it, and still didn't know what to do about it.) This was a beautiful demonstration of the assumption that human beings, especially human beings who have significant things in common, will communicate and converse if given an opportunity, without needing any direction.

I don't know how to do that. I don't even know when I should be trying to do it. People seem to expect me to notice them and relate to them no matter who they are, just because they happen to be there. But if I don't know who people are, I don't know

how (or why) to talk to them. I don't have much of a sense of people-in-general as things to be involved with. And I don't know how to have prefabricated relationships; if I happen to be involved with some person-in-particular, I practically have to learn to talk all over again to develop a common language with that person.

That doesn't necessarily mean I don't care. Sometimes I'm not aware of social cues because of the same perceptual problems that affect my understanding of other aspects of the environment. My visual processing problems are no more the result of indifference than blindness is—are blind people considered insensitive if they fail to recognize people or to respond to others' facial expressions? Sometimes I notice the cues but I don't know what they mean. I have to develop a separate translation code for every person I meet—does it indicate an uncooperative attitude if someone doesn't understand information conveyed in a foreign language? Even if I can tell what the cues mean, I may not know what to do about them. The first time I ever realized that someone needed to be touched was during an encounter with a griefstricken, hysterically sobbing person who was in no condition to respond to my questions about what I should do to help. I could certainly tell that he was upset. I could even figure out that there was something I could do that would be better than doing nothing. But I didn't know what that something was. It's very insulting, and also very discouraging, to be told that if I don't understand someone, it's because I don't care.

Sometimes, though, I'm really not interested. I'm not interested in relationships-in-general, or in people-as-groups. I can be very interested in individuals once I've met them, but I don't feel a need to have relationships in the absence of specific people to relate to. During school breaks I can go for days or weeks without any personal contact with other human beings, and I may get bored, but I don't get lonely. I don't need social contact. And because I don't need it, I have no compelling reason to go out of my way to get it. Mere proximity is no reason for me to become emotionally attached to anyone who isn't interesting to me as a person. Even when someone does attract my interest,

when I do become emotionally attached and desire a relationship with that person, I don't become dependent on the relationship or on the person. I don't need them.

But wait. Because I don't need other people in my life, I'm free, as non-autistic people can never be free, to want other people in my life. Because I don't need relationships with anyone, I'm free to choose a relationship with a someone—not because I need a relationship, but because I like that person. When I make contact with someone, it's special—and not just because a lot of time and effort have gone into producing a response that's a pale imitation of normal social responses. Pale imitations of normalcy aren't worth any of my time and effort at all. When I make a connection it's special because I don't have to do it, but I choose to do it. It's special because I don't generalize very well from one person to another, so everything I do is intensely focused on just that one person. It's special because, having no idea of what's normal and little talent for imitation, I have created something entirely new for that person and that occasion. It's special because I don't know how to take people for granted, so when I'm relating to someone, that person is the most important thing in my world for the duration of the contact.

But I don't stick. That confuses people sometimes. A friend once asked me for assurance that I really wanted to be together. I answered, "I can leave and be just fine, or I can stay and be even better." Isn't it enough to be just fine on my own, and to be able to choose connections that will make my life even better? I have exactly as many relationships as I want. I relate only as myself, only in ways that are authentic to me. I value people only as themselves, not for their roles or status, and not because I need someone to fill empty spaces in my life. Are these the severe deficits in communicating and relating that I keep reading about? Actually, there are some pretty serious deficits, but not in my ability to care. There are deficits in my ability to recognize people who aren't able to care, people who aren't authentic, who don't value me as myself, or who aren't connected at their own cores. It's hard for me to tell when someone is lying. It took me a very long time, and a lot of painful experience, just to learn what lying is. And in the social area, as with everything else, I have

trouble keeping track of everything that's happening at one time. I have to learn things other people never think about. I have to use cognitive strategies to make up for some basic instincts that I don't have. In the social area, as with everything else, there are a lot of things that I don't understand unless someone explains them to me.

That's a special problem in the social area, because one of the things I need help with is deciding whose explanations and advice to accept. Mentors are supposed to be of critical importance to autistic people's successful functioning. A few years ago, when I was just beginning to explore the idea of making connections with other people, I met someone who offered to teach me what I needed to know. He was a doctoral student in special education who worked with developmentally disabled people in a number of community programs. He was warm and gentle and supportive—at least at first. He said he wanted me to be his little brother. He abused me, mentally, emotionally, and sexually. He told me it was my fault. When I told his faculty adviser about it, the professor said that this was friendship, that it was something I needed. What was I supposed to learn from this? I did learn a lot from it. I learned about lies. I learned about betrayal, almost before I learned about trust. I learned about some feelings that are more typical of child abuse and incest: I was just beginning to be aware of things—about relationships, about touching, about trust—that normal babies are born knowing, and he hurt me in ways I could never be hurt as a child, because I never trusted anyone that way when I was a child. I even learned about friendship, by learning about a lot of things that friendship is not.

But probably the most important thing I learned from it was that I am capable of making authentic connections, even if he wasn't. That's a good thing to know. Since then I've learned a lot more about how I can make connections, and about what kinds of people I want to make connections with. The future should be interesting.

## **Being Autistic Will Always Mean Being**

# Different

After reading Temple Grandin's autobiography, someone once asked me if I thought a cattle chute would have helped me. I said I didn't need a cattle chute, I needed an orientation manual for extraterrestrials. Being autistic does not mean being inhuman. But it does mean being alien. It means that what is normal for other people is not normal for me, and what is normal for me is not normal for other people. In some ways I am terribly ill-equipped to survive in this world, like an extraterrestrial stranded without an orientation manual.

But my personhood is intact. My selfhood is undamaged. I find great value and meaning in my life, and I have no wish to be cured of being myself. If you would help me, don't try to change me to fit your world. Don't try to confine me to some tiny part of the world that you can change to fit me. Grant me the dignity of meeting me on my own terms—recognize that we are equally alien to each other, that my ways of being are not merely damaged versions of yours. Question your assumptions. Define your terms. Work with me to build more bridges between us.

## Reference

Grandin, T., & Scariano, M. *Emergence labelled autistic*. Novato, California: Arena Press, 1986.

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